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Cancer patients' family members' experiences of the information and support provided by healthcare professionals

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Abstract

Objectives: This qualitative study aimed to understand the experiences, information and support needs of family members of cancer patients and their satisfaction with the services provided to them as a family member.

Design: Inductive qualitative and critical realist approach to data collection and analysis.

Methods: Purposive sampling was used to identify family members of cancer patients. We conducted semi-structured interviews with 10 participants by means of email, enabling us to explore sensitive topics at a pace appropriate for each participant and gain rich sources of information. We analysed the data using an inductive thematic approach.

Results: Three superordinate themes were identified: information acquisition, seeking support and family members' experiences of cancer. Needs were high, and a complex relationship between information and support was apparent. Many participants felt dissatisfied with the support and information received as it was sometimes inconsistent, incorrect or vague, and some reported deterioration in their own health as a consequence. Online communities were reported as being informative and supportive as the participants felt they could relate to the firsthand experience of the other members.

Conclusion: Improving healthcare professionals' awareness of the type of information and support the family members need is vital for both family members and patients. There is a need for the development of educational and psychological interventions to assist family members in coping when a loved one is diagnosed with cancer, is undergoing or recovering from treatment, or is receiving palliative care.

Keywords

Cancer, email interviews, family, information, support

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In 2015, 359,960 people were diagnosed with cancer in the UK (Cancer Research UK¹). Understanding how cancer affects the family members of cancer patients and learning about their information and support needs are critical. Families can provide a lot of emotional and social support for patients and this can impact on the patient's management of their condition (Carlson et al., 2001).

The substantial psychological distress experienced by the family when faced with cancer is increasingly recognised (Bowman et al., 2003; Hirooka et al., 2017; Holst-Hansson et al., 2017; Kotkamp-Mothes et al., 2005; Luker et al., 2015; Revenson and Pranikoff, 2005). The National Council for Hospice and Specialist Palliative Care Services (1997) defines psychosocial care as care concerned with the psychological and emotional well-being of the patient and family. In contexts where a family member is diagnosed with cancer, other family members are not only faced with the demands associated with providing care but also with those associated with loss and grief (Pinquart and Sorensen, 2007).

Considering the impact of cancer on the wider family is important as decisions about treatment and care are often not made by patients alone but with the help of family members (Revenson and Pranikoff, 2005). This can impact the experiences and the number of needs a family member has throughout the cancer trajectory. For example, when an individual is diagnosed with cancer, their family members often experience high levels of distress and have a number of unmet needs (McDonald et al., 2016). The involvement of family members in decision-making during treatment can also be complex. The patient is the priority, and it is important to balance patient authority with the needs of the wider family (Laidsaar-Powell et al., 2016). Wilkes et al. (2000) interviewed family members of cancer patients receiving palliative care. They found that family members became frustrated and felt helpless when clinicians did not provide information, and this often meant they were not able to make informed decisions about care. Information seeking is an active coping mechanism that can aid a person's psychological adjustment to illness (Weisman and Worden, 1977). It enables people to understand the challenges and consequences that a cancer diagnosis brings, and the need for information has been demonstrated many times among patients and carers (e.g. Clayton et al., 2005; Neumann et al., 2011).

Assisting family members to feel satisfied that their own needs have been met may enable families to feel more capable of supporting the patient (Friðriksdóttir et al., 2011). It is recognised that the needs of informal caregivers should be attended to as well as the patients (Breitbart and Alici, 2009), but there is little research into the experiences of other family members of cancer patients (Berger et al., 2018; Ellegaard et al., 2017; Rutten et al., 2005). For example, a systematic review of 32 studies found that 18 of the included studies focused on the experiences of the patient's spouse or partner, 4 studies explored children's experiences and 10 studies included a range of relationships (Adams et al., 2009). Building on this work, this study aims to explore cancer patients' family members' experiences of cancer and whether they were satisfied with the information and support they received from healthcare professionals and support groups including online communities.

Methods

Design

Qualitative methods were used to enable an exploration of the role of cancer within the broader context of families.

Participants

Participants were purposively sampled and recruited via online cancer support forums and groups, enabling a wide range of people to be contacted. The online communities were English speaking, predominantly based in the UK or USA and open to both cancer patients and relatives. Participants

responded to an advertisement posted on the online community detailing the study, and were eligible to participate if they were at least 18 years of age, had a family member with cancer, were not the primary caregiver and could write and read English. To ensure a range of views were represented, and to keep within the ethical boundaries of not over-recruiting participants for sensitive topics, we anticipated at least 10 participants would take part (Francis et al., 2010). Written consent was gained via email.

Data collection

Interviews were conducted by the first author (J.L.). Due to the sensitive nature of the research, distance interviewing via email was selected as most appropriate (Murray and Sixsmith, 2002). It was believed that email interviews would not only enable participants to respond at a convenient time for themselves, but would also facilitate a more thorough and thoughtful response on the part of participants. In particular, participants would have the time to consider their responses and clarify meaning (Oppermaun, 1995).

Nevertheless, because the data were collected via email, there were a number of ethical considerations to take into account (Meho, 2006). We asked participants to read an information sheet prior to taking part and provided instructions on how to complete the interview (e.g. if possible in a quiet space with no interruptions). To ensure confidentiality and anonymity, we regularly changed the password for the email account used. We also stored data securely and removed any identifiable information from the data.

The interview guideline was developed following a review of the literature and contained six open-ended questions (e.g. ‘What services were offered to you as a family member?’ and ‘What support have you received from healthcare professionals?’). The questions were framed around the participants’ experiences and information and support needs because these were highlighted within the literature as being important to both patients and carers.

Throughout data collection, care was taken not to cause distress to participants. Members of the research team had experience in working with cancer patients, and the interview guideline was checked by all members of the research team and piloted with two participants. No changes proved necessary.

The semi-structured design allowed participants to expand on the posed questions and the researcher was able to ask further questions where appropriate. The tense of the questions was adapted for each participant depending on whether the family member was living or had died. To prevent over-burdening participants, one main question and several prompts were sent in one email at a time, with the next question being sent once a reply had been received.

On average, the interviews were completed within 10 days and there was no limit on the length of time it took participants to reply. Data saturation occurred when no new themes emerged, and recruitment ceased following the analysis of 10 interviews. All participants were sent a follow-up email containing information about where to find out more information and support.

Data analysis

An inductive thematic analysis (Braun and Clarke, 2006) was conducted using participants’ accounts. Two of the authors (J.L. and C.A.) analysed the data independently and initial ideas were compared and noted. Data considered significant to both the research question being explored (Boyatzis, 1998) and the participants were coded and grouped into relevant themes. Potential themes were identified and refined to ensure that the data within each theme was meaningful and coherent while being clearly distinct from the other themes. Clear titles and definitions for each superordinate theme and sub-themes were agreed to by all the authors.

Table 1. Participant characteristics.

Pseudonym	Age (years)	Gender	Relationship to patient	Type of cancer	Country of residence
Rachel	47	Female	Daughter	Prostate	UK
Tom	60	Male	Father	Lymphoma	UK
			Son-in-law	Lung	
Sarah	37	Female	Daughter	Oesophageal	UK
John	33	Male	Son	Prostate	Greece
Amy	23	Female	Daughter	Rare appendix cancer	UK
Carol	49	Female	Sister	Breast	UK
Alice	39	Female	Daughter	Glioblastoma multiforme	USA
Frances	28	Female	Sister	Leukaemia	USA
Anne	60	Female	Daughter	Bladder	USA
Josie	56	Female	Daughter	Skin and oesophageal	UK

The explicit and systematic detail explaining how each theme was identified aimed to provide evidence of a coherent and transparent description of the data demonstrating commitment and rigour (Yardley, 2000). Thematic maps were developed in the course of analysis and were important when assessing how accurately the themes reflected the data (Braun and Clarke, 2006). Sensitivity to context was provided through the inclusion of extracts, and a table with appropriate quotes for each theme was developed to ensure the themes offered a realistic reflection of participants' experiences.

Ethical approval

Ethical approval for the study was given by Staffordshire University's Research Ethics Committee.

Findings

Two male and eight female family members of cancer patients between the ages of 23 and 60 years participated. We excluded three participants as they were either cancer patients or the primary caregivers of cancer patients. Some participants spoke of their experiences of cancer in several of their relatives, including daughters (55%), sisters (18%), a son-in-law (9%), son (9%) and father (9%). The types of cancer also differed between participants (Table 1).

Three major themes were identified within the material: information acquisition, seeking support and family members' experiences of cancer.

Information acquisition

Information needs were particularly high following initial diagnosis as participants wanted to understand what to expect during the cancer trajectory. This need for information and the type of information was largely similar across participants. However, the information they received was often vague and non-specific, and participants reported limited opportunities for clarification, as in the following example:

I have no ability/opportunity to have this explained further or in a way that I understand. (Carol, sister)

Seeking information. Information seeking tended to begin very early in the cancer trajectory. Participants discussed being proactive when it came to seeking information. They wanted to be well informed and believed knowing what to expect would have helped them to prepare and ‘handle the stress’ a little easier. While information was available for family members, the lack of specific information left some feeling ill-informed:

we have the internet and Macmillan stuff but no close support or advice about specifics ... poor. (Tom, father)

Satisfaction with the information received from others. Throughout the interviews, participants’ satisfaction with the amount of information they were given varied. One participant experienced ‘anxiety and stress’ as she felt that the staff were reluctant to answer her questions. Another participant discussed receiving ‘contradictory’ and ‘incorrect’ information and described the experience as ‘walking through a minefield’.

Participants reported often being reliant upon the patient for information; therefore, information was often based on the patient’s understanding and ability to share information. Consequently, participants did not feel well informed and could not always ask the questions they would have liked to:

I was aware that Dad did not mention stages or grades to me, but I felt that I did not want to intrude on his privacy by asking for any further information. (Sarah, daughter)

When information was provided by healthcare professionals, participants were mostly satisfied with the information received about the diagnosis. They felt that the information was ‘complete’ and there were opportunities to ‘clarify anything’ as staff were aware that ‘it doesn’t always go in at first’. In contrast, one participant from the USA was not present at the time of her sister’s diagnosis and did not understand the information she was told, and another participant from the UK described finding out her father’s diagnosis ‘accidentally’: ‘I have had one experience of being given completely wrong information, because the nurse had actually confused my father with another patient’ (Rachel, daughter).

Searching the Internet. Many participants reported acquiring much of their information from the Internet and some described how they were directed to online resources by healthcare professionals. The majority of participants found the Internet a useful resource and were able to find a large amount of information. One participant wrote about the benefits of online communities, stating the support group was the ‘most informative and knowledge gaining place’. This same participant also reported giving ‘more credence’ to those who had lived these experiences rather than to the doctors who ‘learned about this in a book’. Another participant liked the ‘anonymity’ of the online forum she was part of. More generally, participants described the online forums as places where they could talk about how they felt and have their questions answered: ‘I began pouring my heart out there and the response was amazing. Every question I had was answered’ (Anne, daughter).

While the Internet was a useful resource for participants, the lack of specific information about individual cases and conditions meant that participants were not always able to find the information they needed. Moreover, using online resources was problematic for some participants. For example, Carol was not ‘a confident computer user’ and had not accessed some of the online resources available. While participants acknowledged the wealth of information available on the

Internet, they discussed being cautious when it came to gaining information. Some felt that the information can lead you to 'paths that you don't necessarily need to be on'.

Seeking support

Satisfaction with the support received by the participants varied, with some feeling supported and satisfied, and others not at all. The majority of participants reported that their support needs were greatest at the time of diagnosis. However, the needs of participants varied throughout the cancer trajectory. For example, Rachel discussed how the 'things that were once very scary become routine and the next event becomes the scary one'. Nevertheless, the devastating effects of potentially losing their loved ones were omnipresent and the need for support was stated:

I think he just wanted to die there and then in the beginning. At the time I felt like I would be happy to join him, I felt very low too, it was very traumatic for us all. (Sarah, daughter)

Some participants discussed how they were only able to reflect on their emotional needs once their loved one had passed as they had not had the time to do so before. In hindsight, they felt that receiving support earlier would have benefitted both the patient and themselves:

it is only looking back that I realise we would both have been better prepared to cope. I feel sad that I only realised after his death when i had time to reflect. (Josie, daughter)

Support groups. The importance of group support was highlighted by many of the participants. The participants explained that gaining support from people 'who are going through the same' experiences was beneficial. Tom described talking in a group as 'cathartic'. Other participants found the people in these groups 'kind, understanding and supportive', an experience which one participant described as 'truly humbling'. Online communities were viewed 'invaluable' as they provided 'great support' to participants, especially when time to attend face-to-face support groups was limited. Nevertheless, not all of the participants wanted to access these groups.

Satisfaction with received support. One participant reported very positive experiences with the support received. Others reported that the offer of support had come by 'chance' and in a 'disorganised' manner. In some cases, support offered did not materialise, and the difficulties faced when trying to gain support were discussed by a few participants. One participant emphasised how much she had to 'push' to receive these services, but was satisfied with the support she finally received.

Others reported being given a number they could call if they wished to speak to a nurse although one participant did not like to do so directly, later saying that she felt the nurse's 'resources would have been better used on patients themselves'. Despite feeling like this, she also reported that the best form of help for her would have been to speak to a specialist cancer nurse. These ambivalent feelings were present throughout this particular interview.

Several participants relied on the support offered by family and friends rather than healthcare professionals. The importance of having someone to talk to was highlighted and the support received from friends, family and the online groups was emphasised by most of the participants:

We have been and continue to have so many people supporting us. Our church, [the] bible study group that I am in, friends and most important to us family. (Frances, sister)

Family members' experiences of cancer

The impact of cancer on family members. Having a family member diagnosed with cancer was described as 'catastrophic', 'traumatic' and 'stressful'. Some of the participants explained they coped by taking one day at a time:

One of the district nurses told me to 'put one foot in front of the other, and don't forget to breathe' ... I find that a useful philosophy!! (Rachel, daughter)

Other participants talked about how their lives changed. For example, one participant had to stay in a hotel four and a half hours away from her home when her sister was in hospital and another converted his dining room into a bedroom with a hospital bed for his mother-in-law. Financial difficulties following the diagnosis of cancer were also described (e.g. house conversions, transport for treatments). These placed extra demands on participants, and many reported feeling dissatisfied with some of the services available. The physical impact of having a family member with cancer was also apparent:

I was having a very hard time sleeping. I felt like I was going nuts from no sleep. (Frances, sister)

The emotional impact was seen across all participants, with the words 'anxious', 'traumatic' and 'frightened' being used. When her father's cancer returned, one participant 'felt very low' and another used to 'weep' the day before taking her father to see the oncologist. Some participants reported feeling confused and were 'busy just trying to cope'. Throughout the interviews, the emotional impact of cancer was omnipresent and some participants discussed the long-term effects. Following the death of her father, one participant felt her grief was similar to post-traumatic stress disorder and was prescribed antidepressants to help her cope:

I think there are probably a lot of issues that have gone undealt with over the years due to a lack of support and I imagine I will be dealing with them for a long time to come, especially following the death of my Dad. (Amy, daughter)

The relationship between patients' needs and family members' needs. When talking about their needs, some family members did not distinguish themselves from the patient using words such as 'we' and 'us'. While family members themselves did not have the diagnosis of cancer, they too lived through the reality of the disease.

Highlighted by some of the participants was how the patient's needs indirectly affected their own. When the patient was well looked after by professionals, family members also felt supported and satisfied. Similarly, family members felt let down and dissatisfied when the patients did not receive enough help or information:

As a family member I personally was offered no services. By that I mean that my mum was sent home from the hospice and everything was geared toward taking care of her. I was absolutely fine with that and I am not complaining, but if I had had some resources suggested or recommended to me then I might have been able to handle the stress. (Alice, daughter)

The patient was the participants' priority, meaning anything the participants felt came secondary to the needs of the patient. Participants reported 'needing to be brave' and 'cheerful' despite there being 'a lot of tears' when alone. Josie reported being so concerned about her father that she did

not realise that she needed extra help. Interestingly, one participant reported that her father was trying to 'protect' her by withholding information:

I think Dad had seen how anxious the operations had made me, so did not let me in on his worries often and did not tell me about these appointments till he knew it was good news. (Sarah, daughter)

Relationship between information and support. The amount of information the participants received affected the level of support they needed. Being able to understand what was happening improved their experiences and made the situation a little 'less scary'. Participants often made reference to both information and support and did not view them as two separate needs. Feeling well supported was often reported in the context of receiving information rather than being emotionally supported:

face to face support would have allowed me to make specific enquiries about his cancer. (Josie, daughter)

One participant explained how she tried to fulfil her emotional needs by learning as much as she could about everything related to cancer, and she was able to gain 'strength' from increasing her knowledge. She also reported wanting to give others information so they would not 'run into the same lack of support'. However, feeling well informed did not always help participants feel supported. Amy was satisfied with the information she was given during her father's treatment but was dissatisfied with the level of support she received during this time. Thus while information and emotional needs were sometimes linked, they could also occur in isolation from each other:

I would say then that in terms of the information we received during his treatment as to the risks etc, I was definitely satisfied but in terms of the levels of support received then no, I was not satisfied. (Amy, daughter)

Discussion

When people are diagnosed with cancer their family members are also affected. Previous research has focused on the experiences and needs of the main caregiver, suggesting that support and information are vital when a family member has cancer (Kim et al., 2016; Northouse et al., 2012; Swick et al., 2012). Our findings provide insight into the experiences and information and support needs of the family members of cancer patients.

Participants' use of emotive language throughout their interviews suggests the impact of cancer was severe for family members throughout the cancer trajectory, but was greatest around the time of diagnosis. Emotional distress has been reported among family carers of cancer patients (Wheelwright et al., 2016) and this study demonstrates how all family members can experience psychological distress irrespective of the participant's relationship with the cancer patient (e.g. sister or mother-in-law). For example, the impact of losing a father to cancer was demonstrated by two participants, which highlights the difficulties faced by adult children.

In this study, the family members of cancer patients proactively sought out information. The main sources of information used were healthcare professionals, leaflets and the Internet. Each of these sources had its advantages and disadvantages, impacting on the participants' overall experiences of cancer and their levels of satisfaction with the information they received.

Participants' need for information may be explained in terms of the Cognitive Appraisal Theory of Stress and Coping (Lazarus and Folkman, 1984). A person's psychosocial adjustment and how well they cope with a situation are influenced by personal, illness-related and social factors which

are antecedent conditions mediated by their cognitive appraisal. Folkman and Lazarus (1980) suggested controllability is critical in the appraisal of stressors. As a result, one of the most reported forms of coping is information seeking (Cohen and Lazarus, 1979; Hamburg and Adams, 1967). While we did not measure adjustment to the cancer within this study, participants' needs appeared to be affected by their uncertainty about the diagnosis. Moreover, the lack of practical information meant that many of the participants were dissatisfied and did not feel in control. Information needs were particularly high following diagnosis, and the participants often reported that their needs remained unmet at this time. Their satisfaction with information increased as the cancer patient commenced treatment.

The need to understand what was happening was a recurrent theme throughout the interviews and having accurate information can help family members have a better understanding of symptoms and prognosis. Information-seeking can divert attention from distressing thoughts and allow family members to focus on the more practical and useful matters through attention deployment (Lazarus et al., 1974). In this study, several participants discussed being so preoccupied with trying to get through each day that they were often not aware of the indirect effects the cancer was having on them personally. It was only following the death of the cancer patient that some of the participants had time to reflect on their experience. In some cases, this was when the distress was particularly prominent. At this time, other adaptive forms of support are needed to minimise the psychological effects following the death of the patient.

Participants relied on information from healthcare professionals, but found online forums to be the most valuable source of information and support. The exchange of information on online sites proved crucial to several participants and is in line with previous research (Baker et al., 2003; Kalichman et al., 2002). Using the Internet, people are able to share their thoughts relatively anonymously (Wagner et al., 2004) and clarify information to gain a greater understanding (Preece, 2000). The significant value placed on the exchange of information within these online communities suggests that experiential information and support are important for the family members of cancer patients.

The importance of experiential support has been demonstrated among other patient populations (Ziebland and Wyke, 2012) and has become recognised as a key source of knowledge and support in healthcare practice (Locock and Brown, 2010). The current findings suggest that the benefits of experiential support extend beyond the patient so as to aid family members too. Experiential support can act as a form of active involvement allowing people's experiences to be articulated and transformed into a mode of action. This can reduce feelings of social isolation. However, it is important that Internet communities do not become a substitute for face-to-face support since some participants were restricted due to their limited computer skills and work commitments. Instead, formal support should be complemented by the Internet and experiential support to allow optimal support and information for family members.

The findings from this study are important when thinking about psycho-educational programmes for persons having a family member with cancer. It is important for such programmes to highlight the effects of having a family member with cancer; and to educate family members about how important their needs are and what services are available both to themselves and to the patient. Developing a time and cost-effective strategy may alleviate some of the strains placed on the healthcare system as families would feel better informed and supported, and fewer long-term complications may be experienced.

The importance of a good relationship with healthcare professionals is well documented in patient populations (Wagner et al., 2010). This study identified the importance of such a relationship with other family members also. As a result, there needs to be an organisational shift towards a more multifaceted approach to cancer care in which policy makers, healthcare professionals and

key stakeholders (e.g. service users and their family members) explore the different ways to improve communication and support for relatives. In turn, this may impact on the experiences of the family members of cancer patients.

Strengths and limitations

Like all research, this study has some limitations. Participants were recruited from online communities which restricted the participant profile to those who use the Internet. It is possible that the participants in this study had more negative experiences when compared to those not using online communities. Nevertheless, we have identified a number of experiences of family members which previous studies have not explored.

The use of distance interviewing via email enabled us to contact participants from a range of geographical locations demonstrating some similarities of experiences and information and support needs across different countries. However, we relied on participants' literacy skills to collect data and were not able to use non-verbal cues to assist with the interview. Despite this, we were able to collect a considerable amount of data offering insight into the experiences of family members of cancer patients, including their information and support needs.

Future research

Since several participants discussed the importance of online forums in terms of receiving information and support, it would be valuable to explore how those who do not have access to the Internet meet their information and support needs, and whether experiences and needs differ between those who do use online forums compared with those who do not. In addition, understanding the experiences of healthcare professionals and gaining their perspective on speaking with the family members of cancer patients who are not the primary caregiver will be important in gaining a more holistic understanding of how best to improve services and experiences.

Conclusion

The impact of being a family member of a cancer patient was demonstrated throughout this study. It is difficult to know whether receiving information helps a person to adjust due to the informational or supportive elements. In this study, information and support were often discussed simultaneously by all of the participants. This may partly explain why information is often seen as a supportive tool and when participants were satisfied with the information they received they frequently reported feeling satisfied with the support offered too. While information aids family members of cancer patients in the management of the illness and practical aspects of caring, it also helps them to deal with their own feelings of vulnerability.

Sometimes participants reported feeling satisfied with the information they received but not the support. Therefore, it is important to recognise that while information and support sometimes complement each other, both need to be addressed and both influence the overall experiences of the family members of cancer patients. Our findings were similar across all of the participants and did not vary widely by relationship to the patient or by country. They suggest that information and support needs are particularly high following diagnosis and that many study participants felt dissatisfied with the information and support they received from healthcare professionals. Nevertheless, the majority were able to use a number of ways to navigate a complex situation and improve their overall experience.

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Note

1. See <https://www.cancerresearchuk.org/health-professional/cancer-statistics-for-the-uk>

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